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PERSPECTIVES IN REHABILITATION

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Valued activities and informal caregiving in stroke: a scoping review

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ABSTRACT

Purpose: Map the literature about valued activities and informal caregiving post stroke and determine the nature, extent, and consequences of caregivers' activity changes.

Methods: A scoping review was undertaken, searching Pubmed, Cinahl, PsycInfo, and Google Scholar. Two researchers independently identified relevant articles, extracted study characteristics and findings, and assigned codes describing the topics and outcomes. Using thematic analysis, the main study topics and study outcomes were described.

Results: The search yielded 662 studies, 30 of which were included. These were mainly qualitative and cross-sectional studies assessing caregivers' activity changes and related factors, or exploring caregivers' feelings, needs and strategies to deal with their activity challenges. Although caregivers often lost their social and leisure activities, which made them feel unhappy and socially isolated, we found no studies about professional interventions to help caregivers maintain their activities. Over the years, caregivers' activity levels generally increased. However, some caregivers suffered from sustained activity loss, which, in turn, relates to depression.

Conclusion: Loss of valued activities is common for stroke caregivers. Although high-level evidence is lacking, our results suggest that sustained activity loss can cause stroke caregivers to experience poor mental health and wellbeing. Suggestions to help caregivers maintain their valued activities are presented.

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Stroke; informal caregiver; valued activities; social and leisure activities; wellbeing; depression

➤ IMPLICATIONS FOR REHABILITATION

- Not only stroke survivors but also their informal caregivers tend to lose their valued activities, such as their social and leisure activities.
- Although many caregivers manage to resume their valued activities over time, others suffer from sustained activity loss up to at least two years post stroke.
- Loss of valued activities in stroke caregivers can result in lower levels of wellbeing, depression, and social isolation.
- Rehabilitation professionals should screen stroke caregivers for activity loss and assist them in resuming their valued activities and maintaining their social contacts.

Introduction

Providing informal care to a stroke survivor is often demanding [1,2]. Once the stroke survivor returns home from hospital or from the rehabilitation center, most caregivers have to provide extensive care and suddenly must perform activities that were previously done by the stroke survivor, such as household tasks or finances [3–5]. The demands of caregiving can limit caregivers' time for themselves and restrict participation in their own valued activities, such as work, leisure, or family life [1,6]. Caregivers' loss of these activities is likely to be related to a decline in their health and wellbeing [1,2,6]. So far, however, little is known about the nature, extent, and consequences of caregivers' loss of valued activities [6,7]. In addition, review studies [8,9] show that caregiver interventions rarely address this loss. As a result, the best way to help caregivers maintain these activities, if necessary, remains unclear.

We undertook a scoping review to map the literature related to stroke caregivers' valued activities, the consequences of changes in these activities, and possible strategies to help caregivers maintain them. Unlike systematic reviews that bring together evidence to answer a specific research question, scoping reviews have a broad "scope" with less restrictive inclusion criteria. They are conducted to determine what evidence is available on a specific topic and to represent this evidence by mapping or charting the data [10]. Results from this particular scoping review may help define future research issues, support professionals in helping caregivers maintain their valued activities, and improve our understanding of how this can be done most effectively.

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In the context of this review, valued activities were defined as activities that were voluntary chosen by caregivers and of specific value to them, for example, because they help caregivers regain the strength to combine their caregiving role with their family role or social position. Valued activities can be any kind of activity, such as playing a game, reading a book, practising a profession, or going on holiday. Although taking care for the stroke survivor can also be highly valued by informal caregivers, in the context of this review we did not consider this caretaking to be a valued activity [11]. We argued that caregivers are often suddenly confronted with their new care task and, at least at first, this task is usually not chosen but required by circumstances. We also excluded instrumental activities such as "speaking" or "solving problems" from our definition because these activities were assumed to only be a precondition of caregivers' valued activities.

Aim and review questions

The aim of this scoping review was to:

1. Conceptually map the literature according to the main study characteristics (year of publication, country, scientific area, study focus, participants, methods/methodology, methodological quality);
2. Identify existing knowledge related to caregivers' valued activities post stroke and the consequences of caregivers' activity changes (e.g., related to their health or wellbeing);
3. Identify strategies that professionals can use to help stroke caregivers maintain their valued activities;
4. Identify knowledge gaps and areas for further research.

Methods

Framework and search

We used the scoping review methodology frameworks of Arksey and O'Malley [12] and Levac, Colquhoun and O'Brien [13] to conduct our scoping review. Arksey and O'Malley's framework was developed to address existing knowledge about how to undertake scoping reviews [12]. It was further refined by Levac et al., who enhanced the clarity and rigor of the scoping review process [13].

We searched for literature in the following databases: Pubmed, Cinahl, PsycInfo, and Google Scholar. Our search period was May 2005 to May 2016, and we used the following search terms: stroke, caregiving or caregiver, family, spouse, meaningful activity, valued activity, role, occupation, and leisure time. We also consulted subject matter experts (occupational therapists, nurses, sociologists) for useful additional literature.

Inclusion of studies

We included qualitative, quantitative, and mixed-method studies that were written in English and addressed the valued activities of informal caregivers who provided care to community-dwelling stroke survivors on a daily to weekly basis. Two researchers (MW and SJ) independently identified the articles that met the inclusion criteria by title, abstract and full text. Prior to each inclusion step, they used a sample of ten reports to verify agreement in applying the inclusion criteria. Disagreement was solved by discussion. In cases where no consensus was reached, a third subject matter expert's opinion (RS) was final.

Assessing methodological quality

We used the Critical Appraisal Skills Programme (CASP) lists [14] to assess the methodological quality of the studies. Each original study was independently assessed by RS or MW and SJ using the specific list per design (qualitative, cohort, or review study). Any disagreement was solved by discussion. Percentage scores of quality were calculated based on fulfilled items divided by the total number of relevant items. Studies with CASP scores $\leq$65% were considered to have poor methodological quality.

Data extraction

Extraction of the main study characteristics and study findings was done by two researchers (MW and SJ) independently. Findings related to stroke caregivers' valued activities were extracted from all qualitative, quantitative, and mixed-method studies by selecting those text passages and outcomes that were related to caregivers' activities such as their work, leisure, or social activities. Subsequently, consensus was reached about exactly which passages and outcomes to extract.

Next, quantitative outcomes were transformed into qualitative findings by describing the essence of the outcomes in words. This transformation of quantitative outcomes is common in mixed-data reviews and is used so that quantitative and qualitative data can be combined and subjected to qualitative analysis [15].

Finally, the researchers independently described the content of each finding briefly, while staying as close as possible to the original text and meaning. These brief descriptions of content can be referred to as "meaning units" [16]. When researchers had different opinions about the transformation of quantitative data or the content of the meaning units, they discussed the full text to obtain agreement.

Analysis

One researcher (MW) made a descriptive numerical summary charting the main characteristics of the included studies. This was checked by the other researcher (SJ). Subsequently, a qualitative content analysis of all study findings was conducted. To identify the main topics described in the included studies, as well as to determine the main study findings, codes describing the topic and codes describing the content were assigned to all formulated meaning units. This was done by both researchers independently, reaching consensus afterwards. Then, through analyses of the codes, overarching categories of codes and emerging themes, the main topics and the main findings present in the identified studies were described. If a certain finding was exclusively derived from studies with poor methodology, it was marked as "methodologically poor".

Subsequently, overall analyses allowed the researchers to describe the state of current knowledge related to valued activities and activity changes in stroke caregivers. Conclusions about missing research areas could then be drawn. Finally, as recommended by Levac et al. [13], the preliminary findings were shared with stakeholders (stroke caregivers, nurses, allied health care professionals, sociologists) to identify additional emerging issues and validate findings and conclusions.

Results

As shown in Figure 1, the search yielded 662 studies, 30 of which met the inclusion criteria. Of these, 16 were qualitative studies, 10 were quantitative studies, 1 was a mixed-method study, and

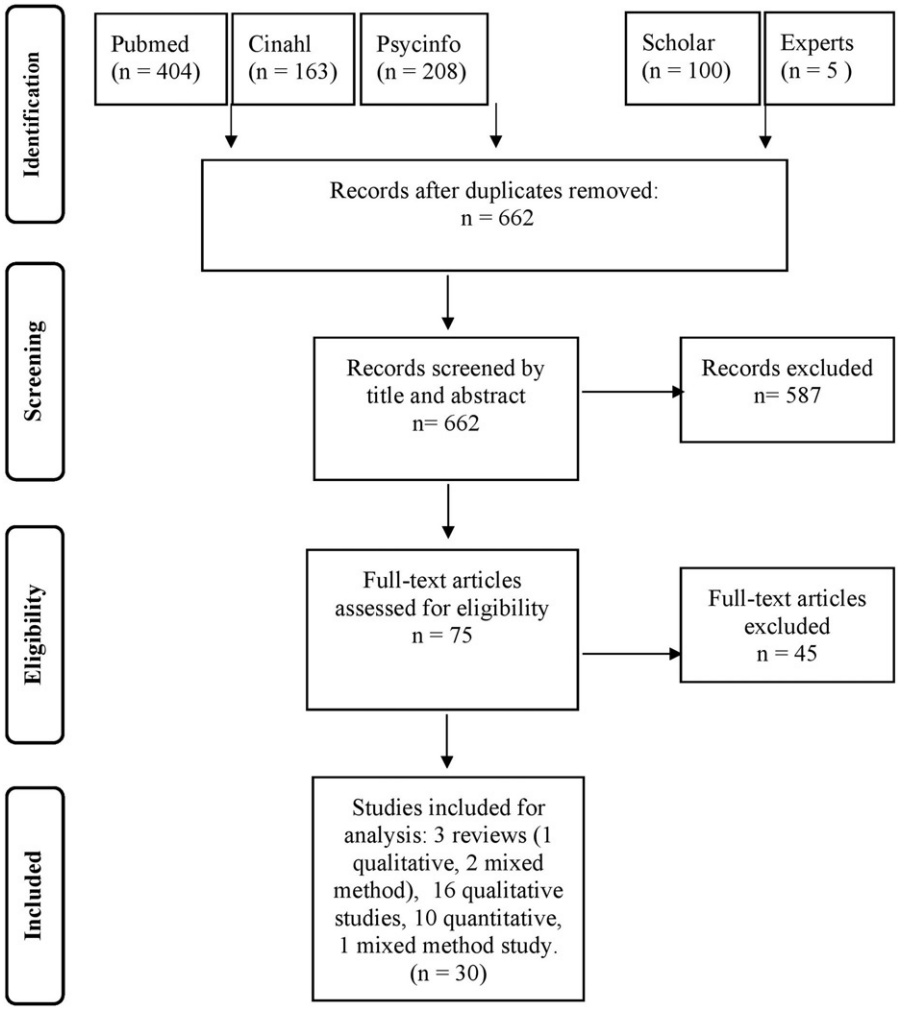

Figure 1. Inclusion of studies.

3 were reviews (one qualitative meta-synthesis, one mixed-method systematic review, and one comprehensive review of qualitative and quantitative data). Initially, our selection criteria had been very broad and included any scientific data related to stroke caregivers' participation in valued activities. After having reviewed a sample of 50 abstracts from the original search strategy, we narrowed the criteria to data that were related to potentially observable valued activities. In the context of this review, "caregivers feeling tired because of all their old and new responsibilities" was therefore not extracted, while "caregivers feeling tired because they had to combine work, childcare, household, and stroke caregiving activities" was. We applied this criterion to all the search results.

Study characteristics

Almost all included studies were conducted in high-income Western countries such as Canada and Sweden. Three studies came from middle-income countries (India, Brazil, South Africa). The topic of valued activities was predominantly studied by researchers from occupational therapy science (14 studies) and nursing science (11 studies). It was furthermore studied by researchers from psychology/psychiatry (6), neurology/neuroscience (6), physical therapy science (2), and language & communication sciences (1). We found eight studies that aimed to identify experiences of stroke caregivers in general, nine that searched for factors relating to wellbeing or life satisfaction and ten that specifically researched valued activities of stroke caregivers and the factors associated with these activities. In addition, three studies investigated how caregivers responded to or dealt with alterations in their valued activities. We found no studies on professional interventions to help caregivers maintain their valued activities.

Participants were mainly women providing care to their spouses or parents. Five studies focused on caregivers younger than 66 years old, three on older caregivers, and twelve on both. In ten studies, the ages were not reported. Overall, the reported mean age of the caregivers ranged from 46 to 64 years (ages ranged from 16 to 86). Measurement time-points of the qualitative data were several days to 18 years post stroke; time-points of the quantitative data were 1 month to 2 years post stroke.

The included qualitative studies mainly used semi-structured interviews to explore informal caregivers' experiences. Some studies used a descriptive approach, while others used an interpretive approach to thematic analysis. The quantitative studies were all cross-sectional or cohort studies. They used a variety of measures, such as the Caregiver Impact Scale (CIS) [17], the Caregiver Burden Scale (CBS) [18], the Life Satisfaction Checklist (LiSat-9) [19], the Occupational Gaps Questionnaire (OGQ) [20], or the Activity Card Sort (ACS) [21]. Of these measures, only the OGQ and the ACS completely consist of questions about daily activities.

The other measures are multicomponent scales from which we only extracted the data about valued activities. The one mixed-method study combined the ACS with open-ended questions. Table 1 shows all the study characteristics as well as the methods of data collection/analyses as described by the authors.

Findings (methodologically poor studies are marked with *, [22–24] are reviews)

Thematic analyses of all study findings revealed that six main topics were described in the included studies. These topics and the related main study findings were as follows:

Activity changes

The studies that described stroke caregivers' activity changes found that caregivers often immediately put aside their own needs and quit many of the activities they had valued before so they could concentrate on the stroke survivor [25–32]. Although social and leisure activities were the most frequently abandoned [23,24,26,28], activity loss was also reported in work [27,31,33,34], cultural and recreational activities [26,35], exercise [31,33], shopping, household and cooking [26,36], sexual activities [37,38], outside activities [26,33,36,39], and traveling [31,35]. Young caregivers reported that caregiving interfered with their family activities and child-rearing tasks [31,34,39]. As time went by, most caregivers gradually developed new routines, dared to leave the stroke survivor alone more often and were able to resume some of their former activities [32,39,40]. This was confirmed by quantitative studies that found that caregivers' activity levels generally improved with time [29].

In some cases, caregivers reported no activity loss at all [25,26,41] or even reported that family activities had increased as a result of the stroke [36].

Reasons for activity changes

Several studies described why activities had changed as a result of the caregiving. Some caregivers explained that their activity loss had to do with the inability to do things as a "couple unit" [42]. For example, the stroke survivor's physical limitations could make activities outside the house difficult [26,30] and, as a result, both the caregiver's and the stroke survivor's activities decreased [30,36,43]. Caregivers often hesitated to engage in activities that were previously done together, because they found it no fun to do them alone or felt guilty because the stroke survivor was not able to go with them [35].

For other caregivers, activity loss had to do with the inability to leave the stroke survivor alone, which prevented them from doing things on their own [22,26,32]. Caregivers who were the spouse or partner of the stroke survivor often experienced a self-imposed sense of responsibility and reconciled themselves to the idea that staying at home was in the best interest of the stroke survivor. They did not want to ask for help from others and, even if there was help from a home healthcare service, they had trouble leaving the stroke survivor [39]. When they did go out, they rushed through their errands and telephoned home frequently because they worried about the stroke survivor's safety [44].

Sometimes caregivers had no options for relief because their social network was limited or unhelpful [31]. All the responsibilities and tasks then fell to them and, as a result, they only had the energy and time to do the most crucial things [31,35,45]. They often had to reduce working hours or quit their job [27,31,33,34] which affected their income and, as a result, limited their activity choices [26].

Relationship between valued activities and wellbeing or health

The qualitative studies that examined the impact of caregivers' valued activities on their wellbeing or health described how the loss of valued activities negatively affected the caregivers' wellbeing. However, if caregivers had the opportunity to do activities that were meaningful to them, their wellbeing and emotional vitality were enhanced [32,33,39,42]. In this respect, although combining work and caregiving was challenging, work was seen as an important activity because it provided caregivers with a source of personal space, enjoyment and a set timeframe for a break from caregiving [32,39]. It also seemed to help stroke survivors to develop their independence [32], which ultimately made caregiving tasks easier.

Also seen as beneficial for the caregiver, as well as for the stroke survivor and the family, was doing things together. When families managed to engage in mutual activities, this often led to a new sense of closeness and wellbeing, which helped the family move on. However, a decline in mutual activities or an asymmetry in activities (the caregiver or family being occupied and the stroke survivor being inactive) often affected the relationship [30,32,40].

According to the quantitative studies in this review, caregivers' higher activity levels were indeed significantly associated with higher levels of positive affect [46], vitality and general mental health [25], and lower levels of role strain* [28], burden [25,41] and depression [29,47]. However, caregivers who worked were slightly more likely to exhibit depressive symptoms than non-working caregivers [27]. Two studies examined the connection between activity levels and physical health, but they found no significant relationship [25,29].

Most of the included quantitative studies did not explicitly differentiate between short-term and long-term caregiving or only researched caregivers during the first year post stroke, so they provided little insight into how long-term activity loss relates to wellbeing. One of the few studies that followed the caregivers up to 2 years post stroke found that, although caregivers' activity levels tend to increase with time [29], on average across the whole sample, the levels of positive affect remained stable during these first 2 years. Also, unlike the first year post stroke, after 2 years, lower activity levels were no longer significantly associated with lower levels of positive affect [46]. However, 2 years out, two other studies found activity loss to still be significantly associated with caregivers' depressive symptoms [29,47].

Caregivers' feelings, needs and wishes regarding activity changes

The studies that examined the caregivers' feelings, needs, and wishes reported that, especially in the early period after discharge, caregivers felt that they were "not having a life of their own" and "not being the person they were before". They missed "breathing space" and felt like "a prisoner in their own house" [32,34,36,45]. Especially when caregivers had little support, had to combine many tasks and were compelled to choose between different roles (i.e., being a partner and caregiver), they felt overwhelmed and experienced sorrow and blame for not having enough strength to do everything [31]. Respite that allowed them to focus on their own activities and needs, even for a few hours, was seen as critical to continuing the caregiving role [22,44,45].

Many caregivers also felt isolated [44,48] due to their reduced social life and related loss of social contacts [36,39,44,48,49]. They needed people who could safely care for the stroke survivor so they could meet up with friends or enjoy some activities of their own, such as going to the gym, gardening or reading a book [35,42].

Table 1. Studies and their characteristics.

Included qualitative studies

Author(s), country, study quality percentage score	Scientific area	Aim/study focus	Type of caregivers, *n* (male/female), mean age (range or SD)	Time since stroke/discharge	Method/design*	Main outcome with respect to caregivers' participation
Arntzen 2015 [30], Norway, 78%	Occupational Therapy Science	Explore stroke survivors' and relatives' negotiations of relational and activity changes post stroke	Relatives of people with mild or moderate stroke who live at home, $n = 12$ (4/8), age: missing	6 months–12 years post stroke (T1)	Semi-structured interviews/thematic analysis (Lindseth & Norberg)	Co-occupation in mutual valued activities + upholding separate activities contributed to reciprocity and helped the family move on
Bastawrous 2015 [31], Canada, 89%	Occupational Therapy Science	Explore daughters' experiences with multiple roles while providing post stroke care	Adult daughters providing care to a parent with stroke who lives at home, $n = 23$ (0/23), age: 47 (38–54)	Some time post stroke (average: 11 months, T1)	Semi-structured interviews/thematic analysis (Braun & Clarke)	Daughter caregivers had to juggle multiple roles and responsibilities. This affected their relationships and valued activities
Barbic 2014 [33], Switzerland, 67%	Health-/Occupational Therapy-/Nursing Science	Provide evidence of the content validity of a working model on emotional vitality in informal stroke caregivers	Spouses, adult children or other relatives providing care to community-dwelling stroke survivors, $n = 30$ (7/23), age: 54 (±16)	Some time post stroke (T1)	Semi-structured interviews/content analysis	Participation in meaningful activities was one of the five aspects found to be relevant to caregivers' emotional vitality
Van Dongen 2014 [32], Austria, 89%	Occupational Therapy Science	Explore how working informal stroke caregivers experience and cope with changes in their daily occupations	Primary caregivers of community-dwelling stroke survivors (wife or daughter), $n = 3$ (0/3), age: 55.6 (49–59)	3–14 months post stroke (T1)	Semi-structured interviews/interpretive phenomenological analysis	Changing activity values and performance appeared to be a strategy for maintaining wellbeing in caregiving. Work was seen as a balancing occupation that contributes to wellbeing
Winkler 2014, USA [42], 78%	Neurology, Language & Communication Science	Explore how caregivers of people with aphasia perceive their roles and responsibilities	Caregivers of stroke survivors with aphasia who wrote blogs about their experiences, $n = 10$ (1/9), age: missing (20–60)	Some time post stroke (T1)	Blogs/passive analysis (Ritchie & Spencer)	The extra tasks affected the caregivers' quality of life and relationships with the stroke survivors. However, they also reported a new sense of closeness and pride in their achievements
Quinn 2014, UK, 100%	Psychology	Explore spousal coping and adaptation to caregiving when their spouse experienced a stroke	Included were studies ($n = 12$) about spouses' perspectives related to stroke caregiving, $n = 125$ (27/98), age: d.i	1 month–12 years post stroke (T1/T1–T4)	Meta-synthesis (Sandelowski & Barroso's technique)	Findings suggested that spouses adopt a range of adaptive coping strategies such as seeking their own space to focus on their own interests
Pierce 2012 [45], USA, 67%	Nursing Science	Examine the dimensions of new family stroke caregivers' emotional strain	Primary persons responsible for providing informal care to the stroke survivors, $n = 73$ (18/55), age: 55 (20–80)	Twice weekly during a year post discharge (T1–T26)	Semi-structured interviews + e-mails/content analysis	Three major dimensions of emotional strain emerged from the data: being worried, running on empty and losing one's self
Tellier 2011 [38], Canada, 67%	Nursing Science	Explore the quality of life of couples after a mild stroke	Spouses of stroke survivors with a mild stroke, $n = 8$ (2/6), age: 56.9 (± 9.2)	3 months post discharge (T1)	Semi-structured interviews/content analysis	Family members reduced their own activities to assist the stroke survivor because complex activities were difficult for the stroke survivor

(*continued*)

Table 1. Continued

Included qualitative studies

Author(s), country, study quality percentage score	Scientific area	Aim/study focus	Type of caregivers, *n* (male/female), mean age (range or SD)	Time since stroke/discharge	Method/design*	Main outcome with respect to caregivers' participation
Bäckström 2010 [39], Sweden, 89%	Nursing Science	Illuminate the experiences of being a middle-aged close relative of a stroke survivor	Close relatives of people with stroke, $n = 9$ (2/7), age: 54 (40–64)	1 and 6 months post discharge (T1/T2)	Semi-structured interviews/content analysis	The caregivers struggled for control and renewal of family life. Work and relief from caring seemed to be essential to managing their life situation
Cao 2010 [35], Canada, 100%	Physical Therapy Science	Explore the perspectives of caregivers of stroke survivors with respect to their own physical activity	Spouses and primary caregivers of stroke survivors living in the same house, $n = 10$ (0/10), age: missing (45–73)	Some time post stroke (2–5 years on average, T1)	Semi-structured interviews/inductive analysis	There had been a change in activities and the meaning of these activities. Barriers to valued activities included guilt and lack of time and energy
Green 2009 [36], Canada, 78%	Nursing Science	Explore mild stroke caregivers' perceptions of factors affecting caregiver strain and quality of life	Wife-caregivers of stroke survivors with mild stroke, $n = 26$ (0/26), age: 58.5 (33–75)	1, 2, 3, 6, 9 & 12 months post discharge (T1–T6)	Semi-structured interviews/conventional content analysis	Caregivers expended considerable time and energy reestablishing control of their lives following a minor stroke
Pierce 2009 [50], USA, 44%	Nursing Science	Determine whether there was support for themes described earlier by a stroke caregiver	Web-users who provide care to a stroke survivor, $n = 36$ (11/25), age: 54 (31–80)	Some times in the first year post stroke (T1–?)	E-mails/content analysis	Caregivers took on new tasks after their loved ones' stroke. Gradually, they learned to manage their situation and ask for help
Thomas 2008 [34], South Africa, 78%	Psychology	Explore the impact of stroke on the family system	Primary caregivers providing care to their spouse or parent, $n = 6$ (2/4), age: 47 (16–67)	1.5 years–13 years post stroke (T1)	Semi-structured interviews/content analysis	Prominent themes associated with caregiving: role changes and occupational and social implications
Brittain 2007 [48], UK, 78%	Nursing Science	Explore the experiences of caregivers looking after a stroke survivor with incontinence	Main caregiver, living in the same house, $n = 20$ (7/13), age: missing (51–86)	7 months–18 years post stroke (T1)	Semi-structured interviews/content analysis	Dealing with incontinence led to restriction of out-of-home activities
Pierce 2007 [40], USA, 67%	Nursing Science	Examine problems and successes in the first year of caring for stroke survivors	Family caregivers, $n = 73$ (18/55), age: 55 (31–80)	Some time in the first year post stroke (T1)	Semi-structured interviews/content analysis	Caregivers struggled to find balance and a new sense of normal in life. Seeing accomplishments and doing things together were helpful
White 2007 [44], Canada, 78%	Neurology, Nursing-/Occupational Therapy-/Physical Therapy Science	Explore the perceptions of caregivers regarding the barriers and facilitators to undertaking the caregiving role	Primary caregivers of stroke survivors, $n = 14$ (7/7), age: majority 50 + (missing)	Some months to about 1 year post stroke (T1)	Focus group interviews + semi-structured interviews/content analysis	A supportive social environment, a well-coordinated healthcare system and accessible community resources are all facilitators to maintaining the caregiver role
Laliberte-Rudman 2005, Canada, 78%	Occupational Therapy Science	Report the occupational experiences of stroke survivors who use wheelchairs and their caregivers	Primary caregivers of stroke survivors living at home, $n = 15$ (2/13), age: 68.1 (44.5–84.2)	Some time post stroke (T1)	Semi-structured interviews/grounded theory	Caregivers found themselves living in a "restricted occupational world", and their participation in valued activities was full of daily challenges

d.i.: data incomplete.
*As reported by the author.

Table 1. Continued.

Included quantitative studies

Author(s), country, study quality percentage score	Scientific area	Aim/study focus	Type of caregivers, *n* (male/female), mean age (range or SD)	Participation measure, time since stroke/discharge	Design	Main outcome with respect to caregivers' participation
Grigorovich 2015 [29], Canada, 87%	Occupational Therapy Science	Determine changes in stroke caregivers' participation over time + related factors	Family members or friends primarily responsible for providing care, $n = 399$ (123/276), age: 58.4 (14.55)	Caregiver Impact Scale, 1, 3, 6, 12, 18 and 24 months post stroke (T1–T6)	Cohort	Participation restriction level improved over the first year post stroke. Factors such as being younger or being employed were related to participation restriction
Cameron 2014 [46], Canada, 100%	Occupational Therapy Science, Psychiatry	Identify aspects contributing to stroke caregivers' psychological wellbeing	Primary caregivers (spouse, son, daughter or other), $n = 399$ (123/276), age: 58.4 (14.55)	Caregiver Impact Scale, 1, 3, 6, 12, 18 and 24 months post stroke (T1–T6)	Cohort	During the first year, caregivers who maintained participation in valued activities reported higher levels of positive affect
Kniepmann[a] 2014 [26], USA, 67%	Occupational Therapy Science	Identify the association of leisure changes with stroke caregiver burden and health-related quality of life	Female spouses of working-age men who had survived a mild to moderate stroke, $n = 20$ (0/20), age: 52.9 (22–65)	Activity Card Sort, 6–24 months post stroke (T1)	Cross-sectional	Providing care to a husband with functional behavior problems was significantly related to more leisure loss. Leisure loss was significantly related to caregiver burden
Oliveira 2013 [28], Brazil, 17%	Nursing Science	Investigate the prevalence of caregiver role strain in stroke caregivers	Caregivers of stroke survivors who had followed in-home care services, $n = 42$ (4/38), age: 46.4 (±15.6)	Caregiver Burden Scale, some time post stroke (T1)	Cross-sectional	Withdrawal from social life and changes in leisure activities were significantly related to caregiver role strain
Sreedharan 2013 [51], India, 17%	Neurology	Study the employment status and social functioning of stroke caregivers	Principal caregivers, $n = 150$ (34/116), age: missing	Questionnaire with culturally relevant activities, 3 months–2 years post stroke (T1)	Cross-sectional	The caregivers' decline in social functioning after stroke was significant. Their employment status was not changed
Kniepmann 2012 [25], USA, 67%	Occupational Therapy Science	Examine activity changes in women caring for their working-age husbands with mild to moderate stroke	Female spouses or partners of a working-age male stroke survivors, $n = 20$ (0/20), age: 52.9 (22–65)	Activity Cart Sort, 6–24 months post stroke (T1)	Cross-sectional	Eleven caregivers reduced or quit some of their valued activities. These caregivers reported higher levels of burden and lower vitality and general mental health
Cameron 2011 [47], Canada, 87%	Occupational Therapy Science, Psychiatry	Determine the contribution of stroke survivors' behavioral and psychological symptoms to caregivers' distress	Primary caregivers, $n = 399$ (123/276), age: 58.4 (14.55)	Caregiving Impact Scale, 1, 3, 6, 12, 18 and 24 months post stroke (T1–T6)	Cohort	Caregivers reported more depressive symptoms when they experienced more lifestyle interference
Vincent 2009 [43], Canada, 50%	Psychology	Compare burden of caregivers of stroke survivors discharged home from two different health care facilities	Main caregivers, $n = 156$ (46/110), age: 64.4 (±11.5)	Impact on the Caregivers Social Life, 3 weeks & 3 and 6 months after discharge (T1–T3)	Cohort	Up to 3 months post stroke, the social life of caregivers of survivors discharged home from a rehabilitation unit was more affected that those of survivors discharged home from a hospital
Carlsson 2007 [37], Sweden, 100%	Neuro-/Occupational Therapy Science	Compare stroke survivors' and spouses' life satisfaction with norm values	Spouses of stroke survivors, $n = 56$ (17/39), age: 59 (34–79)	Life Satisfaction Checklist 9-item version, 1 year post stroke (T1)	Cross-sectional	The leisure activities and sex lives of patients and spouses were affected
Ko 2007 [27], USA, 83%	Neuro-/Nursing Science	Examine how stroke caregiving affects employment, compare working and non-working caregivers	Informal stroke caregivers (spouses, daughters or significant others), $n = 132$ (34/98), age: 57 (±12)	Employed (part-time/full-time) yes or no, 3–9 months post stroke (T1)	Cross-sectional	36% of the caregivers reduced their working hours or stopped working. Working caregivers received more assistance from family members

[a]Family caregiving for husbands with stroke: An occupational perspective on leisure in the stress process.

Table 1. Continued.

Included mixed-method studies						
Author(s), country, study quality percentage score(s)	Scientific area	Aim/study focus	Type of caregivers, *n* (male/female), mean age (range or SD)	Participation measure, time since stroke	Method/design*	Main outcome with respect to caregivers' participation
Kniepmann[b] 2014 [26], USA, qual: 67%, quan: 33%	Occupational Therapy Science	Examine how caring for partners with stroke and aphasia impacts caregivers' activities	Partners of individuals with aphasia post stroke, $n = 12$ (2/10), age: 61.5 (37–73)	Activity Card Sort, Occupational Gaps Questionnaire, ≥6 months post stroke (T1)	Descriptive statistics + semi-structured interviews/–	Caregivers experienced occupational loss, primarily in cultural activities/low demand leisure and social activities
McGurk 2013 [24], UK, 80%	Psychology	Identify the problems faced by informal carers of those having aphasia after stroke	Included were studies ($n = 14$) on informal caregivers of stroke survivors with aphasia, $n = 521$ (gender and age: d.i.)	N.a., several days to 14 years post stroke (n.a.)	Systematic mixed method review	Caregivers of people with aphasia experienced difficulties in social and leisure activities and employment, and had little support and respite
Pellerin 2011 [23], Canada, 60%	Occupational Therapy Science, Neuro-ethics	Describe the challenges faced by relatives of people with stroke in accomplishing their daily activities and social roles	Included were studies ($n = 17$) that examined participation of relatives of survivors in general, and the role of rehabilitation for relatives and ethical issues (*n*, gender and age: d.i.)	N.a., some time post stroke (n.a.)	Narrative review	The social participation of relatives was characterized by a reduction in interpersonal relationships and leisure. In rehabilitation, there is no consensus about what should be done for relatives

d.i.: data incomplete; n.a.: not applicable; qual/quan: study quality with respect to qualitative/quantitative data collection.
*As reported by the author.
[b]Occupational changes in caregivers for spouses with stroke and aphasia.

As time went by, caregivers gradually felt calmer and experienced a sense of freedom and more joy in their activities [30,32,39]. Caregivers who were able to maintain their previous activities despite their caregiving task described these activities as more purposeful than before [35].

Dealing with activity changes

The studies that examined how caregivers dealt with their activity changes noted that, particularly in the early phase after discharge, caregivers worked hard to support the stroke survivor and the family while trying to keep their heads above water. They learned not to reflect on their own circumstances too much and just carried on [26,39]. However, with time, they became more concerned about their own needs [30] and began a process of reprioritizing their activities and better dealing with their activity challenges [32]. They had to accept that certain personal and mutual activities could not be resumed. However, they also realized that at least some activities were important to maintain despite the great upheaval in daily life (e.g., a yearly camping trip). They made sacrifices but, by being creative, they also developed new valued activities or resumed the same ones by adapting them to the new circumstances [30,32]. They also negotiated with the stroke survivor and other family members regarding the use of shared and separate time, and mutual and individual activities [30], and learned to ask for help* [50]. When caregivers had to give up their jobs, they found it helpful to replace the missing "breathing space" gained from work with joyful activities, such as listening to music [32].

Who is especially "at risk" for activity loss

Several qualitative and quantitative studies reported that some caregivers were more at risk for activity loss than others. They described how caregivers who took care of their spouse or partner were more likely to suffer from activity loss than other family members/friends [29,30]. Also, younger caregivers [29,38], caregivers who remained employed [26,29,33], provided higher levels of assistance [29] or provided care to stroke survivors with poorer physical or cognitive functioning, poorer community participation or little progress [29,32,41,43,49], resumed their valued activities less often. However, one study found no association between stroke severity and caregivers' activity restriction* [51]. Regarding the caregiver's gender, the findings were also inconsistent: One study found gender to be unrelated to caregivers' activity changes [29], while another study found the decline in social activities to be more profound in men* [51].

Because most of the above studies either took their measurements only shortly after stroke (up to 6 months) or did not differentiate between short-term and long-term caregiving at all, the findings of this review gave little insight into which caregivers are especially at risk for long-term activity loss. However, one quantitative study that did investigate relatively long-term caregiving, found that caregivers who were younger, provided higher levels of assistance and provided care to stroke survivors with lower levels of community participation, were significantly more likely to suffer from activity loss at 2 years post stroke [29]. Specific data on risk factors present at later points in time were not available.

Connections between the topics found

Figure 2 gives a brief overview of the six topics mentioned above as well as the main findings per topic. It also displays the connections between these topics as described within the different studies (the red arrows represent the reported causal relationship as described within the qualitative data; the blue arrows describe the

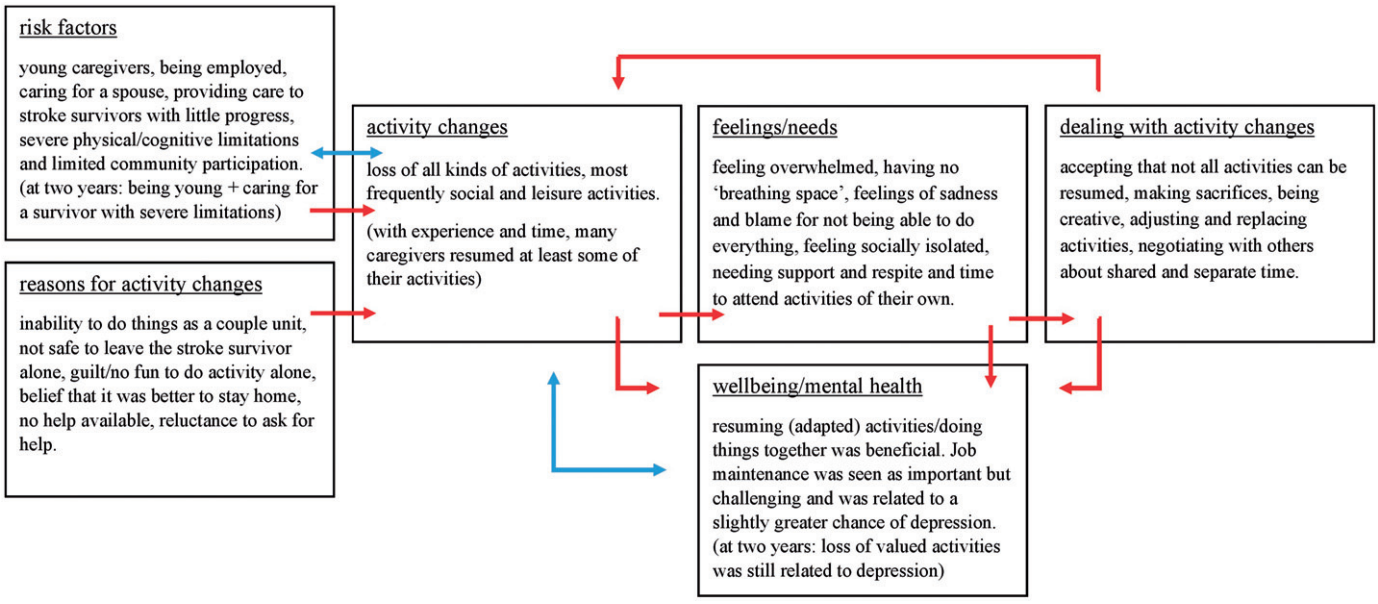

Figure 2. Overview of the topics and main findings present in the included studies. Arrows indicate the causal relationships as suggested or described in the studies (red: reported causal relationship found in the qualitative data;blue: associations found based on correlations in the quantitative data).

found associations as based on the correlations present within the quantitative data).

Discussion

This scoping review identified a range of studies about valued activities and caregiving post stroke. Although all these studies investigated different aspects of this concept and we found no controlled trials that clarified how stroke caregiving, activity loss and wellbeing precisely influence each other, qualitative studies gave some insight into how they may be related. Together, findings indicate that, at least in the first period after the stroke, caregiving often results in a decline in valued activities which can lead to social isolation and poor mental health and wellbeing. If, in this case, caregivers either are supported by others to continue their activities, or are able to accept their situation and adapt their activities to the new circumstances, their activity levels generally increase and their wellbeing is enhanced. However, in some specific cases (such as in young caregivers or in case of stroke survivors with severe limitations) caregivers tend to suffer from sustained activity loss, which, in turn, is related to higher levels of depression.

The findings of this review are in accordance with findings from other studies, (e.g., related to dementia and elderly care), which show that informal caregiving indeed results in a loss of social and leisure activities, which, in turn, can increase caregivers' levels of stress and depression [52–54]. However, increased participation in social activities, sports, music, or religious activities was shown to reduce depressive symptoms in these caregivers [53,54], as well as in older people in general [55].

Because several studies found that engagement in activities can protect against the negative effects of caregiving and improve caregivers' mental health, it seems important that professionals screen stroke caregivers for activity loss and, if necessary, help them resume their activities. Also, activity engagement should be incorporated into existing caregiving interventions as a default part of caregiver education [53,54]. However, as shown in this review, the available literature offers little insight into what strategies are effective in helping caregivers maintain their valued activities. Moreover, the literature did not clarify how exactly these activities can contribute to a satisfying social life and mental health and wellbeing. It also did not clarify which activities are especially vital for caregivers to maintain, or at what point it is better to reprioritise and let go of some activities to avoid exhaustion.

Therefore, before adequate strategies to help caregivers maintain their valued activities can be developed, there needs to be a better understanding of how valued activities relate to wellbeing. The "loss of self" frequently mentioned by caregivers who report no opportunities to engage in the activities they value most [45,56] may explain why their wellbeing is often affected. Because a person's activities and social connections in daily life seem to be highly related to his or her feelings of identity [57,58] and maintaining an acceptable sense of identity is essential to wellbeing [58–60], identity theory may be helpful in further clarifying the relationship between caregiving, valued activities and wellbeing. Furthermore, theory about balance of activities in daily life [61] could help explain what mix of different activities (and rest) seems to be ideal in particular cases.

What can be done to help now?

The findings of this review suggest that, although we lack a thorough insight into the precise benefit of activity maintenance and what exactly helps caregivers maintain their activities, at least something can be done to improve caregivers' wellbeing and prevent their social isolation and depression. Based on the findings of this review, it seems important that health professionals explain to caregivers the benefits of taking time for themselves and maintaining some activities and interests of their own. Especially in the first phase post stroke, when caregivers often forget about their own needs, professionals should help caregivers become aware of their activity priorities and support them in finding practical solutions to maintain these activities.

Furthermore, professionals could support caregivers in their negotiations with others to allow them some time away from the stroke survivor. When activity loss is unavoidable, professionals can help caregivers adapt to their new reality and seek out alternative activities that suit their needs. Also, since doing things

together can be beneficial to both the caregiver and the stroke survivor, professionals could help find ways to undertake these mutual activities and arrange some assistance if necessary.

Social support is essential to the caregivers' ability to manage their situation after discharge [62]. However, in contrast to what caregivers often expect, help from others is often limited and tends to decline over time [62–64]. Therefore, professionals should inform caregivers that it is important for them to maintain their social network so that they will have the opportunity to ask for help and maintain their social activities, which these caregivers often value highly.

Because work can be an important part of the caregiver's identity, a stable source of social contact and a welcome distraction from caregiving, it seems important that professionals also help caregivers maintain their jobs. However, although work provides caregivers with the necessary income and subsequent activity opportunities, combining work with caregiving can also be highly demanding and the advantages will not always outweigh the disadvantages. In this respect, one study [65] found that, among women taking care of a stroke survivor living in their own household, engagement in a full-time job was related to better psychological wellbeing. However, another study [66] found that combining caregiving with work outside the house had no positive effect on caregivers' stress levels, except when they cared for a person with a mental disability. Therefore, because work is beneficial for some caregivers and not for others, professionals should be cautious when offering advice on whether caregivers should attempt to maintain their jobs.

Future research

Future research should attempt to clarify the relationship between stroke caregiving, valued activities, identity and related factors such as mental health and wellbeing. In particular, there is a need for quantitative research into long-time caregiving, related activity changes and mental health or wellbeing.

As was shown in this review, many studies only measure activity loss as a part of bigger constructs, such as "caregiver burden". However, future research that aims to specifically identify and understand caregivers' activity loss should use instruments that specifically measure this loss (e.g., ACS, OGQ). Subsequently, interventions that have the potential to enhance the valued activities of caregivers who are vulnerable for activity loss and mental health problems, such as depression, should be developed and tested for their effectiveness.

As the studies in this review mainly included female caregivers, future research should also address male caregivers and their activities so that future interventions can be tailored if necessary. Furthermore, it seems useful to study the activities and experiences of caregivers from non-Western backgrounds. As one's identity is shaped by social and cultural norms [67,68], comparing the experiences of caregivers from Western and non-Western countries could add to our knowledge of how specific valued activities, in specific social circumstances, relate to a person's identity and wellbeing.

Strengths and weaknesses

The strength of this study was the extensive overview of knowledge available about valued activities and caregiving post stroke. This topic is highly relevant to stroke rehabilitation policies, but has not been given much attention in the scientific literature until now. Because many scoping reviews do not sufficiently operationalize the method of synthesis used [69], we made efforts to clarify and describe our data synthesis method as precisely as possible. We also assessed the methodological quality of the included studies and marked the low methodological quality findings. However, as is common in scoping reviews, we did not adjust our findings based on their methodological quality.

In general, we found few studies that explicitly aimed to examine the relationship between stroke caregiving and activity changes. To be able to at least give a first overview of what is known in the field, we also had to extract findings from studies that only tenuously examined this topic. Although, as a result, the literature we found described various subjects and participants and used different methods and measures, most findings indicated that stroke caregiving results in a loss of caregivers' valued activities, which, in turn, affects caregivers' mental health or wellbeing. However, there are no controlled trial studies available, so there is no quantitative evidence that confirms the causal relationships between these topics.

Moreover, as the included studies varied widely with regards to the cultural context or time of measurement after stroke, it is not yet clear in what cases exactly what findings are valid. As a result, conclusions drawn in this study can be seen as global. Nevertheless, this review gives a good first impression of issues related to activities valued by stroke caregivers.

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